

## Ethical Issues for Qualitative Research in On-line Communities

### Introduction

Internet technology has developed rapidly in recent years, and offers new possibilities for researching, particularly when working with hard to reach groups who may benefit from a move away from more traditional methodologies. The research has been informed by various methodologies, and is flexible in its application and nature, varying from an analysis of the content of web pages (Jones, Zahlm and Huws 2001), to complex discourse analytic techniques of ‘electronic conversations’, (Denzin, 1999). One of the most common uses of the Internet as a research tool has focused on the use of online questionnaires, via web page delivery or e-mail, and has proved useful in providing novel insights into research questions (see for example Coomber’s ,1997 investigations of drug dealers) as have on-line focus groups, and real-time interviews (O’Connor and Madge, 2000).

Other qualitative research methods which can be adapted for Internet research are those based on observations. Techniques of participant observation are particularly amenable to Internet research with listservs (online discussion forums where messages are posted asynchronously, e.g. Sharf, 1997). Mann and Stewart (2000) cite various advantages of such a methodology, most notably the benefit of being able to ‘lurk’ effectively online. ‘Lurking’ can take place without detection if non-participant, covert observation is required, and without the various barriers associated with age, gender and race if overt participant observation is the goal.

The increasing use of online methodologies raises some ethical issues which are unique to such research in addition to more 'traditional' ethical concerns. The degree of concern will vary depending on the method of research employed. While the participants of online questionnaire based research have the choice whether to complete the survey, the observation of natural conversations in real-time chat rooms and on listservs by 'lurking' do have serious ethical considerations associated with them regarding invasion of privacy.

The focus of this paper will be to examine ethical issues that need to be considered when researching in an online forum. It will firstly discuss concerns around privacy and confidentiality, and cite the work of Sharf (1999) who has proposed a set of research guidelines which go some way to addressing many of the questions raised in the discussions of ethics. The final sections will focus on power issues surrounding Internet use and discuss new power differentials, which may emerge in on-line forums. Throughout the paper reflections will be made on a piece of work recently completed by the authors using the arena of on-line discussion groups whose membership comprises of people considered to be on the autistic spectrum as a source of research.

Recent papers have highlighted the increasing use of Internet technologies by autistic people (e.g. Dekker, 2000; Blume 1997), as both a forum for self-advocacy movements, and a 'safe' way of meeting other members of the 'autistic community'. Dekker (2000, p.1) has claimed "the internet is for many high functioning autistics what sign language is for the deaf". The Internet is therefore considered to be a

particularly useful tool in establishing contact with ‘autistic groups’, and ensuring that their opinions are reflected in the current research.

### **Privacy and Confidentiality**

Concerns regarding the ethical basis of online research have been voiced by researchers (e.g. Schrum, 1995; Sharf, 1999; Mann and Stewart 2000). To date no universally accepted ethical guidelines have been developed, although several researchers have provided a grounding for the development of ethical guidelines specific to such work (e.g. Sharf, 1999, ESOMAR, 1999). The main concerns centre on notions of privacy and confidentiality, informed consent and narrative appropriation. Can we expect the same ethical principles to apply to online research that apply to more traditional research conducted in a face to face situation?

With regard to privacy and confidentiality, Sharf (1999) suggests that e-mail communication is analogous to a letter or phone call, with private intentions, but capable of being intercepted. However, unlike phone calls, and more easily than letters, e-mail can be more instantaneously copied or re-directed, unknown to the writer. Most communicators do not regard this to be a serious threat, in that they don’t expect a researcher to be gathering their commentary as data to be analysed, and continue to exchange deeply personal information, often encouraged by the anonymity that the Internet can offer. The most vulnerable populations therefore are online self-advocacy groups, where information is freely exchanged which can be personal to the sender, but if forwarded, or intercepted by a researcher can provide an interesting research base. This raises obvious ethical concerns if the potential

researcher fails to obtain the consent of the creator of the message before using it in their research.

The nature of self-advocacy groups online may complicate discussions of privacy for such participants. Should a message posted to a bulletin board be considered private in the same way as an e-mail sent from one individual to another? The message posted to a group could be considered 'private' in the sense that only group members or those with related issues are the intended audience, not researchers. These important issues of privacy and confidentiality must be resolved if research on the Internet is to develop in an ethically sound way.

Recent work completed by the authors seeks to investigate the use of discussion lists by adults with autism. Such notions of privacy and confidentiality discussed above played a key role in the consequent methodological choices made by the researchers. The on-line discussion groups joined for the project all had message archives which were not available for public viewing, and hence were considered 'private' in the sense that only group members had access to them. In addition to this, many messages from groups had an explicit footer attached to them requesting that messages not be forwarded to a second party before informing the creator of the message. This highlights the firm beliefs in the groups that messages were intended to be private, and confidentiality must be respected. This was adhered to at all times in our recent work.

Elgesem (1996) suggests six principles of fair information processing that discuss issues raised above, and states that personal data should be reasonably guarded against risks such as loss, unauthorised access, modification and disclosure. Kramarae

(1995) further highlighted the complex nature of security. Although researchers can promise confidentiality in the way they use the data, they cannot promise that electronic communication will not be accessed and used by others. Researchers therefore need to be careful about the assurances they give to participants regarding confidentiality. This was not a huge issue in the current work as the research in on-line discussion forums was solely collecting what the group was discussing in their daily 'conversations'. The researcher remained a silent member of the list and did not require the list to generate any additional information for research purposes.

However slight the problem of interception of information may be, electronic communication does run this risk and this presents a complex paradox as to the extent to which researchers should alert participants to potential problems, given the negative effect this may have on participation levels. This will be more problematic for certain groups than others. For example work by Coomber (1997) employed online surveys to investigate the views of drug dealers. The choice of methodology enabled a previously inaccessible group to become a potential research population. In addition to the potential pitfalls of interception, there was the problem of the sender of communication being potentially (and normally) traceable.

Coomber was alerted to problems of confidentiality from two sources. The first was a USA lawyer who advised him that the USA and UK had arrangements for the sharing of information involving criminal activity, and that Coomber was laying himself open to being subpoenaed to provide identities and/or e-mail addresses of participants. The second source was from potential participants who queried how he could be sure that his line was not being 'tapped' by law enforcement agencies. Coomber resolved such

issues by running the results through a server whereby only the numerical data was collected, without any personal description of the contributor. For the more suspicious participant, Coomber included a printable text version of the questionnaire that could be downloaded then sent anonymously via regular mail.

### **Who owns the data collected?**

In a related point, Elgesem (1996) proceeds to discuss the question of ownership of data. Elgesem's principle of disclosure limitation proposes that personal data should not be communicated externally without the consent of the individuals who supplied the data. However, Kitchin (1998) questions who owns a message which has been posted on a bulletin board? Should such messages be considered as having a copyright in the same sense as articles, essays, and the like, or are these public properties as they appear on a public notice board? Schrum (1995) proposes that individual rights and copyright issues must be considered and addressed the moment the researcher decides to become an "electronic ethnographer".

Mann and Stewart (2000) deepen the discussions by questioning whether we should distinguish between data collected from private or semi-private sources such as e-mail or closed chat-rooms, and those accessed through open access such as bulletin boards and newsgroups. If we accept that we should gain permission before using the message for research, is it enough to gain the permission from the owner of the group, or the individual concerned? Should we use pseudonyms if the individual in question can not be traced, and continue to cite the narrative? Does a person's narrative become public property if it appears on a public discussion forum?

These are questions that require deep consideration by the potential researcher. Ferri (2000) believes that a fundamental question for research concerns who is the intended audience of an electronic communication, and does it include a potential researcher? If the web page or message posted to a discussion list is not intended by the writer as potential data for research, should we as researchers be using it as such without the permission of the creator?

These questions were dealt with directly by the authors in their research by the methodological approaches chosen. The researcher's made initial contact with the list owners of the group, and introduced the idea for the research project to them. When access had been negotiated, a message was posted to the group clearly stating the research intentions and the assurance that no posts would be taken from the group before the prior consent of the individual creators of the message had been obtained.

### **Informed Consent and Narrative Appropriation**

This point is closely related to the question of informed consent and narrative appropriation. Sharf (1999) discusses when and in what form consent is required from people in an online research project. "What constitutes an invasion of privacy on the Net? If data collection of other peoples talk is not unlawful, does it follow that it is ethical to do so?" (p.247). If investigators recruit respondents in an online survey or interview, those who do respond have made a conscious decision to do so. However, if the research is focusing on naturally occurring discourse, those who are studied can not choose to exercise the same sorts of control over consent. Ethical concerns also arise regarding potential exploitation – how are the results to be used, and to whose benefit? Will the finished piece be made available to those who have participated in

it's creation, and will such texts be beneficial to those to which it refers? The researcher must carefully address such issues before commencing research.

The authors are aware that questions surrounding informed consent and narrative appropriation are particularly relevant to work with people with autism and other 'disabilities', particularly with reference to power differentials, which are sometimes apparent in the research relationship. These issues were addressed by the authors in their work in a number of ways. As discussed earlier, negotiation was first made via the list owner who was given details about the project. Some list owners replied to messages requesting additional information about the project and it's intentions, which was provided. Once the list owners had agreed to participation in the project, a message was posted to the group which clearly identified the position of the new member as a researcher, and gave some details as to the aims of the project. List members were encouraged to contact the researcher directly if they had any concerns with the project. Some queries were raised, but once a fuller explanation of the nature of the project was given to individuals, their concerns were eradicated. Further attention was given to informed consent by the decision to contact individual members to expressly gain permission to use their postings as examples in the final write up.

The choices made by the current researchers raise issues surrounding dilemmas as to informing participants of the research, and the consequent risk of the 'Hawthorne Effect', (Heiman 1999). Participants may refuse to participate in the research if they are aware of the project, which on this occasion did not happen, as well as the risk of interfering with the natural environment due to the awareness of the presence of the



researcher. In the current research project concerning the use of discussion lists by people with autism, ethics were taken as paramount in resolving this dilemma. The project was not about ‘observing’ the idiosyncrasies of people with autism, but about engaging them in meaningful research which would promote self-advocacy, and document the ways in which people with autism interact in highly sophisticated ways.

Concerns regarding potential exploitation of participants when using this method of research were addressed by the main aims of the project. These were to enable the ‘voice’ of people with autism to be heard in academic writings, through researching naturally occurring discourse in an on-line forum that consisted of people on the autistic spectrum. A summary of the final piece will also be made available to members via a posting for the list owner to distribute to the list.

Recent work by Jones, Zahl, and Huws (2001) uses the Internet as a tool for obtaining ‘First-hand Accounts of Emotional Experiences in Autism’. The authors stated their awareness “... of the contentious ethical issues relating to privacy, confidentiality and informed consent involved in obtaining information from the World Wide Web” (p.394), and took precautions to use fictitious names and not reference the original websites used in the study. In light of this, Jones et al selected five websites authored by individuals with autism and analysed the contents of the sites in order to investigate any common themes of emotion. Several categories were identified and discussed. It is during this discussion that the intended confidentiality is somewhat breached. By citing “catchphrases” from homepages, the authors of the sites became easily identifiable to the reader who has knowledge of autism homepages. Throughout

their discussion it remains unclear as to whether the consent of the individual authors was obtained prior to publishing their re-interpreted texts.

This raises important discussions as to the process of interpretation. If the aim of the research was to glean insights into autism by gaining first-hand accounts, then the interpretations of the texts by the researchers surely should be given to the individuals concerned. This would firstly enable consent to be obtained from the individuals concerned for the extracts to be used in research, and secondly to offer an opportunity for the creators of the web pages to challenge the interpretations of emotions given by the researchers. The literature would lead us to conclude that the use of the Internet by individuals with autism and related conditions is part of a movement of self-advocacy. Blume (1997) has discussed how historically people with autism have been spoken for by others, and a consequent traditional image of people with autism as an eternal child, unable to speak for themselves has emerged. Blume suggests that this is changing as many adults with autism find their 'own voice' online. This process of 'giving voice' via online methodologies will largely be ignored if the individuals concerned are not given the opportunity to reinterpret texts and guide the researchers, giving informed consent for their narratives to be used in research.

### **Towards a Set of Guidelines**

Sharf (1999) has described her research with an online breast cancer group, and has developed a process that addresses many of the major ethical dilemmas facing researchers. Initially Sharf was a mute member of the list, then began printing postings which she found interesting, and formed a research question. Immediately

she informed the group, and re-introduced herself as a researcher to the list at regular intervals for the benefit of new members. Sharf eventually wrote a paper using the information gathered from the discussion group, then before publication contacted all the individuals whose quotes she wanted to use, personally requesting their consent to use them. In the e-mails she included the intended quote, and an offer for the individuals to read the finished piece. This gave the participants a chance to challenge any interpretations made by Sharf of their text. Through her work, Sharf has developed the following guidelines for researching online groups.

1. Before starting an investigation and throughout the duration of the study, the researcher should contemplate whether or not the purposes of the research are in conflict with or harmful to the purpose of the group. Conversely, the researcher should consider whether the research will benefit the group in some way – e.g. helping to legitimise the groups function.
2. The researcher should clearly introduce himself or herself as to identity, role, purpose, and intention to the on-line group or individuals who are the desired focus of the study.
3. The researcher should make a concerted effort to contact directly the individual who has posted a message that he or she wishes to quote in order to seek consent.
4. The researcher should seek ways to maintain an openness to feedback from the e-mail participants who are being studied.
5. The researcher should strive to maintain and demonstrate a respectful sensitivity toward the psychological boundaries, purposes, vulnerabilities, and privacy of the individual members of a self-defined virtual community, even though its disclosure is publicly available. (Sharf 1999, p.253-254).

Mann and Stewart's (2000) more general practical guidelines for researching on the Internet can supplement these specific guidelines. The first issue to consider is that of informed consent. In more traditional face to face research, the participant will usually sign a statement, and is given the opportunity to ask questions about the research before committing to the programme. This is obviously problematic for online research as the participant rarely physically meets the researcher, and Mann and Stewart suggest some measures for obtaining consent, which may be suitable for various methodologies. When researching by e-mail interviewing a statement about the study and accompanying consent form could be sent as an attachment, to be both printed and posted, or copied into a second e-mail and re-sent. However, whether consent obtained via an e-mail reply is as valid as a signature remains hotly debated. A second option for an e-mail-based project is to create a website explaining the purpose of the study, any practical arrangements, and important information about the researchers, the address of which could be contained in an e-mail to the participants. A download facility for an electronic consent form could be included, requesting that participants post the completed consent form to the researchers.

Real-time online focus groups pose separate problems for obtaining consent as it is unlikely that the researcher will be able to obtain informed consent from participants at the time of the actual chat session or focus group. Mann and Stewart (2000) suggest the use of a conference area to supplement the session, which allows statements about the study to be read and agreed ahead of the actual research session. If created ahead of time, this method can also enable participants to post any queries or questions they may have back to the researcher before the research session commences, or contact the researcher directly via e-mail.

Mann and Stewart (2000) do however acknowledge that obtaining informed consent for participant observation in discussion groups can be more problematic, as can the crucial question as to whether informed consent needs to be gained before observation begins. In face to face participant observation work, informed consent is rarely obtained. Denzin (1999) chose to follow this lead and never obtained the consent of his participants before quoting postings, neither did he identify himself to the group as a researcher.

As described earlier, the work of Sharf (1997) was much more open, with her identifying herself to the group as a researcher immediately after framing a research question. Personal consent was obtained from individuals before using their quotes, giving participants the opportunity to validate her interpretation of their meanings in text, which addresses many of the issues discussed above. Our work described with online discussion forums for people with autism has been informed by the work of Sharf.

Ethical problems which are faced by researchers in an online environment are not therefore dissimilar to those encountered when conducting qualitative research in face-to-face research. In addition to notions of informed consent, ethical problems faced by researchers in both mediums include the power of the researcher to interpret the data collected. Interesting discussions surround the interpretation of interview transcriptions where participants give views that the researcher disagrees with, (Kitzinger 2000). The dangers of 'speaking for' others is particularly key for people with autism, who have traditionally been denied their own (autonomous) voice.

Blume (1997) has suggested that this is changing, and adults with autism are finding their own voice, notably in online environments.

### **Power and the Internet**

Related to ethics are power issues in Internet research, which need important consideration. Several discussions have taken place concerning power issues in Internet research. Mann and Stewart (2000) discuss the loss of social cues online, which may inform power relations in face to face situations, and Dubrovsky et al (1991) further cite evidence that discussion groups online tend to be less dominated by those with high status. The nature of online discussion groups means that they can consist of a wide range of people offering several discourses surrounding a topic. Discourses that can be accessed range from 'expert'/professional knowledge, to experiences of family members and those directly affected. Online discussion groups may therefore provide an alternative pool of language resources from which to draw identities. Bowker (1999) suggests that these 'linguistic opportunities' offered within online environments enable people with disabilities to 'reconstruct more empowering identities', as more discursive themes surrounding the self are made available.

The Internet therefore seems to be an ideal research tool for conducting unbiased research. However, other researchers disagree, arguing that virtual spaces remain constrained by power exchanges implicit in class, race, and gender, and by default can not be equally friendly environments for everyone due to their domination by white, middle class, Western men (Kramarae, 1995). Baym (1995) and Spears and Lea (1992) suggest that the awareness of such social cues do remain active online, and in addition to these, there are new social processes of domination and marginalisation

with which qualitative researchers may have to contend. For example, the organisation reflected in the domain name can lead to power differentials, and some closed chat rooms insist that new comers are identified as such.

Important issues also surround the language in which most interactions on the Internet is conducted in. English is not necessarily the first language of many users, and issues surrounding interactions in second languages and the cultural implications of this should be considered, in addition to questions surrounding how neutral, particularly gender-neutral language is. Many researchers would contend that language is never gender-neutral (for example Burr, 1995), and is always constructing the social world (Curt, 1994).

New power differentials also begin to emerge concerning the 'usability' of websites and chat rooms. In synchronous chat rooms (where the reply is immediate), those who have 'voice' are those who can type the quickest to make their expressions 'heard', (Mann and Stewart, 2000). Hence we observe a power shift towards those with proficient typing skills. This is less true for asynchronous discussion lists where both the reading of a message and the posting of a reply may be delayed, giving those with less typing proficiency equal opportunities to have their 'voice heard'.

In addition to discussing power differentials in a specific 'virtual' environment, wider issues remain regarding the type of research methodology employed, notably questions surrounding participatory and emancipatory research, (Duckett and Pratt, 2001). The current research seeks to challenge the status of 'expert' in issues surrounding autism in line with several group ethos' which firmly positions people

with autism as the ‘experts’ and not the professionals who have the power to diagnose them ‘officially’. Participants in the research were therefore seen more as collaborators in the research process, rather than ‘subjects’ of investigation, (Duckett and Pratt, 2001). Once the potentially empowering nature of the research was highlighted with the focus on self-advocacy, and the rejection of the study of groups as an ‘oddity’, the researchers were welcomed into the groups.

## **Conclusions**

Using the Internet as a research tool gives promising opportunities for obtaining a rich and dynamic picture of events, drawn from a variety of stances. While the ethical concerns associated with using the Internet for research can be overcome by decisions taken by individual researchers, we need to encourage a set of generally accepted guidelines for qualitative Internet research which will respect our sources of ‘data’.



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